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From Data to Action Using Surveillance To Promote Public Health

Examples from the Pregnancy Risk Assessment Monitoring System (PRAMS)

EXECUTIVE SUMMARY

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About This Booklet

This booklet highlights selected examples from the larger, more comprehensive book entitled *From Data to Action: Using Surveillance To Promote Public Health, Examples from the Pregnancy Risk Assessment Monitoring System (PRAMS)*. The complete book also chronicles the successful translation of PRAMS data into public health action and contains more than 40 examples of states using surveillance data to effect changes in public health programs and policies. All of the examples are based on data collected from PRAMS, a population-based surveillance system of women who have recently given birth to a live infant. These examples illustrate the critical role that maternal and child health surveillance data can play in effecting improvements in the content and delivery of services for women and children.

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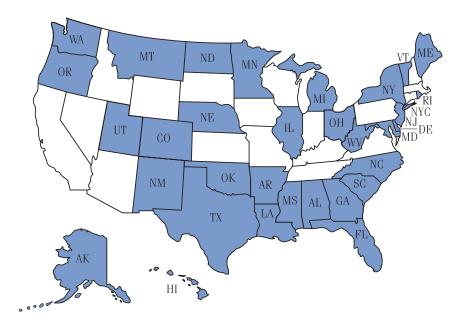
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PRAMS. Pregnancy Risk Assessment Monitoring System

The Pregnancy Risk Assessment Monitoring System (PRAMS) is part of the Centers for Disease Control and Prevention (CDC) initiative to reduce infant mortality and low birth weight. It is an ongoing, state-specific, population-based surveillance system designed to collect information on self-reported maternal behaviors and experiences that occur before, during, and shortly after pregnancy.

PRAMS generates statewide estimates that can be used as measures of perinatal health among women who recently delivered a live infant. Each participating state uses a standardized data collection method developed by CDC. PRAMS staff in each state collect data through statewide mailings and follow up with nonrespondents by telephone. Because PRAMS data are state and population based, findings are generalizable to an entire state's population of women who have delivered a live-born infant.

Since PRAMS began in 1987 with five states and the District of Columbia, it has grown tremendously. As of 2002, 32 states and the city of New York have PRAMS projects through cooperative agreements with CDC. PRAMS surveillance now covers approximately two-thirds of all births in the United States.





Introduction: Moving from Data to Action

The definitive measure of a surveillance system's success is its contribution to improved understanding and prevention of adverse health events. One of the primary objectives of PRAMS is to provide high-quality data that can be used for planning, modifying, and evaluating public health programs and policies to benefit pregnant women, their infants, and their families.

The transformation of public health surveillance or research data into usable information can be referred to as translation. PRAMS surveillance data can be incorporated into public health decision making, or translated, in a variety of ways. In this booklet, examples show how PRAMS data have been used by states to:

- Set priorities—establish priorities for programs, services, or resources.
- Change policies—inform and justify decisions to modify state health policies.
- Change programs—modify existing public health programs, develop new programs, or adjust the content of programs.
- *Identify new resources*—support the appropriation of new resources for programs and services.

Each case highlights the crucial role that partnerships play in the successful application of these data. This is demonstrated at the outset of action, when raising the visibility of an issue is needed, and at the fruition of action when a policy or program is changed or when resources are found to support programs.

PRAMS states have used their data to focus on a variety of special maternal and child health issues. Topic areas featured in this publication include unintended pregnancy, tobacco use, violence, prenatal care, folic acid, infant sleep position, and breast-feeding.



Unintended Pregnancy

Unintended pregnancy is widespread in the United States. Nearly one-third of babies born in the United States each year are the result of an unintended pregnancy, defined as a pregnancy for which, at the time of conception, a woman either wanted to be pregnant later (mistimed) or did not want to be pregnant at any time (unwanted). 1-3 Pregnancy intention is related to infant outcomes such as low birth weight1,4,9 and to maternal behaviors such as smoking, 1,4-7 drinking, 1,6 illicit drug use,8 failure to take prenatal vitamins,⁵ and failure to

initiate prenatal care visits.^{1,7}

The Board of the **Oklahoma** State Department of Health (OSDH) used PRAMS data to develop a policy statement supporting a request for additional appropriations for family planning and teen pregnancy prevention during the 1994 legislative session. The Institute for Child Advocacy in Oklahoma and the county health department administrators were instrumental in contacting and educating legislators regarding unintended pregnancy. In addition, extensive statewide community outreach was initiated. PRAMS data were incorporated into presentations that were given to various health professionals and community groups by the Maternal and Infant Health staff; more than 1,500 community members received information on unintended pregnancy. These efforts generated tremendous support, and many people who felt strongly about this issue contacted their legislators to support additional funding for family planning.

As a result, the Oklahoma State Legislature appropriated \$605,000 in 1994 to the Oklahoma Department of Health Family Planning Program for the expansion of community-based family planning services targeting high-risk, underserved, low-income women and men. Two new nurse practitioners and one public health nurse were hired in rural areas, and a new clinic site was opened. Additional medications, particularly Depo-Provera, were purchased to meet high demand. The same year, the legislature also appropriated an additional \$500,000 to reduce the waiting list for tubal ligations and vasectomies by increasing the availability of these services.

In 1996, the Oklahoma State Legislature again appropriated funds totaling \$2 million for family planning programs to continue providing community-based education, to open additional clinic sites, to hire more staff across the state, and to increase the availability of tubal ligations and vasectomies. As of 2002, OSDH continues to receive appropriated funds for providing sterilization services to family planning clients. PRAMS data on unintended pregnancy are used to validate the need for funding.

danoma

The Family Planning Program at the South Carolina Department

The Family Planning Program at the South Carolina Department of Health and Environmental Control used PRAMS data to evaluate its state-specific performance measure regarding unintended pregnancy for the Title V Block Grant and to make the prevention of unintended pregnancy a priority in South Carolina. As of 2001, health districts across the state were using a variety of approaches to address unintended pregnancy. These include:

 Increasing access to family planning clinics and appropriate methods of birth control.

- Integrating family planning services with other services at the health department, for example, offering counseling and birth control methods to clients seeking women's health, family support, and services for sexually transmitted diseases (STDs).
- Developing partnerships with private physicians to provide family planning services.
- Implementing educational interventions within communities.

For example, in the Catawba Health District, the family planning staff participate in workshops at Clinton Junior College and offer "Laundromat Lunch and Learn Classes" focusing on attitudes, knowledge, and behaviors related to

family planning and STD/HIV prevention. In Jasper County, the district social worker provides family planning education and counseling to teens at the Family Life Center at Jasper County High School 2 days per week. In the Trident Health District, family planning education is provided at health fairs, in classes in the community, and on the campus of the College of Charleston.





Tobacco

Cigarette smoking during preg nancy contributes to a number of adverse birth outcomes, including spontaneous abortion, stillbirth, fetal death, low birth weight, prematurity, and intrauterine growth retardation. Smoking is the most important known preventable risk factor for low birth weight, a leading cause of fetal and neonatal deaths.10-12 Postpartum exposure to environmental tobacco smoke also puts infants at increased risk for Sudden Infant Death Syndrome (SIDS) and several other health problems, including lower respiratory infection, ear infection, and asthma.13

Alabama PRAMS data demonstrated higher smoking rates among pregnant women receiving Medicaid than among pregnant women not receiving Medicaid. In 1996, the Alabama Department of Public Health, in collaboration with the University of Alabama, Birmingham, used these data to win \$2.5 million as part of a grant from the National Heart, Lung, and Blood Institute. This money was used for a program designed to stop or reduce smoking among pregnant women who receive prenatal care in county health department clinics in eight counties. The intervention, SCRIPT (Smoking Cessation-Reduction in Pregnancy Trial), was a 5-year project consisting of a patient education program using a self-help guide and video, with assistance provided by trained staff members. Initial results from the intervention were published in the American Journal of Obstetrics and Gynecology in 2000.14 The authors reported that SCRIPT partici pants were more than twice as likely to quit smoking as members of the control group. Because SCRIPT has been shown to be effective, prenatal care and maternity care staff in the Alabama Department of Public Health are being trained using SCRIPT methods as part of a "best practice" for caring for pregnant smokers in Alabama. The free training, which is carried ut the bugbout the state, began in October 2001 and will continue for years.

The success of the SCRIPT program in Alabama resulted in the formation of the Alabama Tobacco Free Families (ATOFF) Program. The Alabama Department of Public Health and the University of Alabama, Birmingham, received \$4.4 million from the National Cancer Institute to further reduce smoking in the eight SCRIPT counties by expanding the focus to include all women of childbearing age and their male partners. The intervention is aimed at increasing public awareness and knowledge of tobacco risks to the mother, fetus, and infant by targeting messages through community organizations (schools, churches, and work sites), professional organizations (health care organizations and providers), and mass media outlets. PRAMS data are being used to monitor smoking rates among preg nant women in the state. The data also serve as a resource to organizations participating in the intervention.

A governor's task force in **Florida** to PRAMS to support the collecused PRAMS data in the 1997 Florida lawsuit against the tobac co companies. The purpose of the lawsuit was to recover smokingattributable expenditures made by Florida's Medicaid program. The lawsuit resulted in the allo cation of \$11 billion in tobacco settlement money to the state of Florida, which awarded \$50,000 per year to the Florida Depart ment of Health for programs to prevent tobacco use. Some of these funds have been allocated

tion of an expanded sample of teen-aged mothers; the number of teen mothers in the Florida PRAMS sample has increased from about 500 to nearly 1,000 per year. The prevalence of smoking before, during, and after pregnancy among the teen popu lation is being examined using PRAMS data. In addition, these data are being used to assess the impact of smoking on low birth weight and infant mortality in the state.







Violence

Physical violence against women during pregnancy is recognized as a serious health concern for the mother and the baby. 15
Physical assault resulting in abdominal trauma can lead to fetal loss; early onset of labor; and delivery of a preterm, low-birth-weight infant. Physical violence also may contribute to fetal bone fracture, rupture of the mother's uterus, and antepartum hemorrhage. 16,17

The **Alaska** PRAMS project shared 1996-1997 date with the Alaska Special Supplemental Nutrition Program for Volume 1/2 facts, and Children (WIC). These data indicated that women in Alaska receiving supplemental nutritional benefits through the WIC program were four times more likely to report physical abuse during the 12 months before pregnancy or during pregnancy than nonprogram participants. These findings were used to raise awareness about physical violence among WIC recipients. As a result, a WIC team focusing on domestic violence was formed. This team participated in the "10 State" domestic violence health initiative sponsored by the Alaska Family Violence Prevention Project. The purpose of the project was to develop and implement a statewide plan for a comprehensive health care system response to domestic violence. The following are three key accomplishments from this project:

- Community assessment of local resources for victims of domestic violence and an effort to strengthen resources for victims, as well as work toward domestic violence prevention.
- Revision of questions on the statewide WIC application, including the addition of a code to collect data on the prevalence of domestic violence in the WIC population.
- Increased domestic violence screening and the active referral of WIC participants. Screening is done at each 6-month certification of all 25,000 WIC participants in the Alaska WIC program.



Prenatal Care

Prenatal care is recommended for all pregnant women because of its potential to improve the

health of mothers
and infants. Inadequate use of prenatal
care has been associ-

ated with increased risk for low infant birth weight, premature births, neonatal mortality, infant mortality, and maternal mortality.³

A study by the **Color. to** Department (P blic lear than 1 E) zir nement used 1997–1998 PRAMS data to examine the level of prenatal care and selected birth outcomes among documented and undocumented immigrant women in Colorado. Undocumented women could not receive prenatal care through Medicaid, but could receive emer gency care for labor and delivery. The results of the study described the lack of prenatal care and the higher prevalence of negative birth

outcomes among undocumented women. These data were included as part of a larger report to the state legislature. As a result, the Colorado state legislature passed a bill in the 2000 session allowing undocumented women to enroll in a Medicaid health maintenance organization (HMO) and receive prenatal care services at any time during pregnancy. Although no funds were allocated in the legislation, Medicaid health care providers can now pro-

vide prenatal care to undocumented women through a pilot project that is monitored and evaluated by the Colorado Department of Health Care Policy and Financing.



Washington State Department of Health (DOH) used PRAMS data to monitor prenatal care provider discussion about maternal risk behaviors. Find ings from PRAMS data suggested that providers do not always provide all pregnant women with information about important prenatal care procedures, such as genetic testing; maternal risk factors, such as family history of birth defects or genetic diseases; and alcohol-related birth defects. Based on these data, Washington State DOH took several actions:

- Informed perinatal health care providers statewide and nationally about these issues through publications and presentations.
- Developed a "Genetics and Your Practice" CD-ROM and distributed it to health care providers. The CD addresses



the issue of providing differential counseling to clients based on race, ethnicity, or other demographic factors.

 Used PRAMS data to increase the visibility of these issues through development of new maternal and child health performance measures focused on provider education.

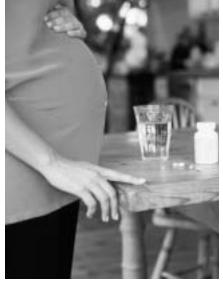
In addition, using PRAMS data on p. nat. care provider discus

sion, the Washington State
Chapter of the March of Dimes
collaborated with the Swedish
Medical Center on a successful
grant application. They were
awarded \$100,000 per year for
3 years from the National March
of Dimes Foundation to develop
and implement a statewide proj
ect to improve preconception and
prenatal health education offered
to women by their health care
providers.



Folic Acid

Multiple studies have established that increasing folic acid con sumption just prior to pregnancy and during the first trimester reduces the incidence of neural tube defects. Recent research indicates that folic acid supple mentation also may reduce the incidence of placenta-mediated pregnancy complications, cer tain congenital anomalies of the heart. and orofacial clefts.



New York State used PRAMS data on knowledge of folic acid as part of two successful grant applications in 1999. The Congenital Malformations Registry

was awarded a cooperative agreement with CDC (\$100,000 per year for 5 years) to initiate a surveillance program to track trends in folic acid knowledge and use among pregnant women in upstate New York. These funds also were used for an educational campaign (billboards, brochures, and other media) to increase awareness among reproductive-age women, as well as maternal and child health providers and educators, of the benefits of folic acid intake during the childbearing years.

The Neural Tube Defects (NTD) Surveillance and Recurrence program was awarded a cooperative agreement with CDC (\$50,000 per year for 3 years) to develop an outreach component for its surveillance system. Now, women with NTD-affected pregnancies are contacted to make sure they are referred for genetic counseling and receive information about folic acid to help prevent NTD reoccurrence in future pregnancies.

New York State



he Fumily Hanning Program in West Virginia used PRAMS data in 1997 to demonstrate the needfor greater folic acid awareness. The Family Planning Program received \$15,000 from the Appalachian Regional Commission, the West Virginia Chapter of the March of Dimes, and the West Virginia Folic Acid Council to develop the Folic Acid Educa-

tio Priect, 'em ntelfn n July to December 1999.

The Folic Acid Education Projectwas designed to increase publicand professional awarenessabout the importance of precon ceptional use of folic acid to pre-vent birth defects. The projectshared information about folicacid and its benefits with women-

c'ch dbearing age throughout West Virginia via displays in



A statewide toll-free number was maintained to accept calls about folic acid concerns and to answer requests for materials; this num ber continues to be in service. Professional educational materials on folic acid were distributed to public health programs including Family Planning, Right from the Start and Maternity Services, WIC, and Children with Special Health Care Needs. In addition, educational sessions on precon ception planning and the benefits of folic acid were held. In one southern, rural jurisdiction, McDowell County, the education project was expanded to include the distribution of multivitamins. Multivitamins with folic acid were distributed to family planning providers to be given free of charge to participating women. By the conclusion of the project, 2.500 bottles of multivitamins were distributed as a way to emphasize the importance of folic acid consumption and to encourage reproductive-age women to get in the habit of taking folic acid.





Infant Sleep Position

Positioning an infant for sleep has been identified as a modifiable behavior that can decrease the risk for SIDS. Consistently placing a healthy baby on its back to sleep for naps and at night has been found to reduce the risk.²¹ SIDS is a diagnosis for the sudden death of an infant less than 1 year of age that remains unexplained after a complete investigation, which includes an autopsy; examination of the death scene; and a review of the baby's and/or family's medical history, including an assessment of symptoms or illness prior to the infant's death.22

The **Georgia** Department of Human Resources Sudden Infant
Death Syndrome and Other Infant Death (SIDS and OID) Work
Group regularly uses PRAMS data. The working group has received
\$100,000 in state funds to coordinate and promote SIDS
risk-reduction and education activities throughout Georgia
using an interagency work plan in collaboration with the
Georgia Public Health SIDS and OID Information and

Counseling Program and the SIDS Alliance of Georgia.

on sleep position to the Georgia Maternal and Infant Health Council (GMIHC). GMIHC used these data, along with information from other sources, to initiate the adoption of a revised position statement on supine sleep position. This position statement fully supports "back sleeping" as the safest sleep position for healthy, full-term infants. It was distributed to all birthing and pediatric hospitals in the state and is available on the Georgia Public Health Web sit

Programmatic changes have also resulted from SIDS and OID Work Group's use of PRAMS data:

- Training programs about sleep safety and SIDS have been devel oped that incorporate information from PRAMS. The curricula for these programs have been tailored to meet the needs of various groups, including public health nurses, child-care providers, pre-hospital personnel, and child fatality review teams.
- PRAMS data demonstrating racial differences in the prevalence of
 positioning infants on their backs to sleep have provided the basis
 for the current SIDS risk-reduction outreach initiative to the African
 American community. Activities have included a public forum to
 address the issue and to develop strategies to lower risk in the
 African American population, a statewide billboard campaign, and
 a bus card initiative on Atlanta-area transit authority buses.

North Caro

The North Carolina Back to Sleep (BTS) Campaign for SIDS Risk Reduction is a statewide education and awareness cam paign aimed at increasing the public's understanding about SIDS and ways to reduce the risks for SIDS. The North Carolina BTS Campaign has used PRAMS data to provide a measure of the statewide prevalence of placing infants to sleep on their backs and to identify characteristics of families and babies at increased risk for SIDS. This information has assisted in the targeting of media messages. PRAMS data are also being used to track trends in infant sleep position over time in the state.

The North Carolina BTS Cam paign was awarded \$40,000 in fiscal year 1999–2000 to use a

multifaceted approach
to increase awareness
of infant sleep position
and to lower SIDS risks.
The campaign focused
on women and their
families as well as on

the health care community. In 2000, more than 800 health professionals and lay health advisors participated in training or presentations that included

PRAMS data; participants included SIDS counselors, perinatal educators, health educators, par enting educators, and members of the SIDS Alliance of the Car olinas. The campaign also target ed licensed child care providers and dispensed educational mes sages to over 9,000 caregivers. More than 300,000 posters, information sheets, light-switch covers, and foto-novellas (comic book-like publications with pho tographs as illustrations) were distributed, along with news releases in newspapers and on radio and television.

The SIDS Community Education **Outreach and Training Demon** stration Project used PRAMS data in a grant application to demonstrate level of need and to identify specific populations at increased risk for SIDS. The project received \$16,130 for fiscal year 2000–2001 from the CJ (Carly Jenna) Foundation for SIDS to maximize the educa tional outreach of the existing network of SIDS counselors, to strengthen the effectiveness of the North Carolina BTS Cam paign, and to focus on popula tions most at risk for SIDS such as African Americans and Native



Americans. One of the compo nents of the education outreach strategy of the BTS Campaign was to enhance local SIDS awareness and risk-reduction community education programs that are managed by SIDS coun selors at county health depart ments throughout the state. The project entailed developing train ing materials, media packets, and community contact forms for use in SIDS community outreach training. Materials and a toolkit to assist SIDS counselors in edu cational outreach and audience targeting were developed.

Breast-Feeding

Breast-feeding is recognized by national and international authorities as the single best way to feed infants.23 Breastfeeding is associated with fewer episodes of infectious illness among infants and healthier relationships between babies and mothers. It has also been shown to be cost-effective for families. A meta-analysis found that breast-fed children have higher cognitive function than formula-fed infants, especially among low-birth-weight infants.24-28



PRAMS data on statewide breastfeeding initiation and duration prompted staff at the **Maine** Medical Center (MMC, the state's largest hospital, accounting for 18 percent of all births) to exam ine breast-feeding practices in

their hospital. A study was designed and implemented in 1997. The-study results, along with a comparison with state-level findings from-PRAMS, were used to encourage the MMC to become more "baby-friendly" and to initiate stronger intervention in the Neonatal Inten -

sive Care Unit (NICU) of the hospital. The breast-feedingeducation program was expanded, and support for lacta tion consultants and their programs was strengthened. -



Since the initial study, the MMC has made a number ofadditional changes to increase the breast-feeding rate inthe hospital:-

- Instituting the March of Dimes' breast-feeding module in the NICU.
- Requiring all new nurses to spend time with a lactation consultant one-on-one to get a good understanding of the referral process.
- Updating family practice residents, pediatric residents, and obstet ric practitioners regularly on breast-feeding issues.
- Convening a multidisciplinary group every other month to isc as lactation-related issues.
- Creating a lactation consultant resource team in several units
 (Obstetrics Clinic; Maternity, Labor and Delivery; Family Practice
 Clinic; NICU; Pediatric Clinic; and Barbara Bush Children's
 Hospital). Two nurses from each unit are trained in lactation
 issues and are the designated resources for their unit.

Looking Ahead

This *From Data to Action* booklet represents some of the fruits of the hard work and commitment of state and CDC PRAMS staff and their partners dedicated to improving the health and the lives of women, their infants, and their families. Now that PRAMS has expanded to include 32 states and 1 city, representing approximately two-thirds of all births in the United States, creative and effective applications of PRAMS data to influence maternal and child health will become more widespread.

To Learn More about PRAMS-

To learn more about PRAMS, *call* CDC's Division of Reproductive Health at (770) 488–6260 or *write* to: Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, Division of Reproductive Health, 4770 Buford Highway NE, Mail Stop K–22, Atlanta, GA 30341–3717.



To *download* this document or to order copies of this publication, please visit our Web site: http://www.cdc.gov/nccdphp/drh/srv_prams.htm.

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